Experiences in public dialogue on biotechnology

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Why am I here?

- How do we identify "the public"
  - never as a single body
  - no consensus
- How to get into a dialogue with it/them?
- Overview of our attempts to do this.

Emerging technologies

- Exodic thinking which insists on looking 'beyond the horizons that keep appearing before us as science develops'
- 'Moral vision has to precede research or we will be constantly in a reactive legal position, seeking to justify what is already unfolding, or struggling to find a political move or linguistic turn to allow political peace'

Challenges

- Surfacing
- Direct or neo-liberal democracy?
- Opinion leaders, civic and private organisations are influential
- values only stabilise in conflict
- Technologies themselves are in constant flux
- Heroic events become theatrical

Purpose

- Project:

How much ethical weight should be given to public opinion in genomic governance?

How do we determine when a policy is fair and promotes public trust?

- Consultation:

Include a breadth of perspectives on an issue, within a forum that treats participants equally and takes their views seriously.

Adjudicating "Public Interest"

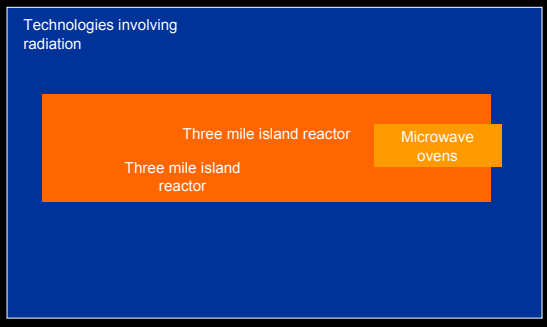
- *…when approaching complex policy matters, we should actively seek out moral perspectives that help to identify and explore as many moral dimensions of the problem as possible.*

Sherwin, S. 2001. Toward setting an adequate ethical framework for evaluating biotechnology policy. Ottawa: Canadian Biotechnology Advisory Committee. http://cbac-cccb.ca/

Representative Approach

- Understand and assess underrepresented or unarticulated perspectives
- Substantive engagement with the values and meanings that may not readily be represented in the market or dominant culture
- Important clarification may come from perspectives that are widespread in a population but unarticulated in polemical discourse

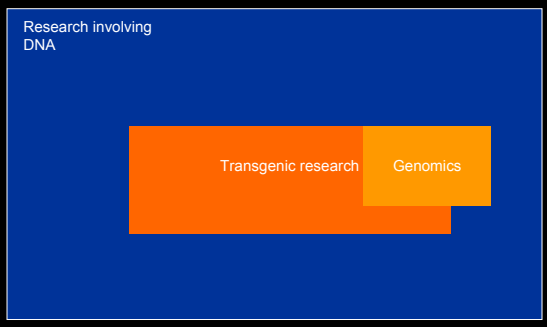
Risk and stigma



Dilemma

- Perception of technologies depends not on formalised scientific taxonomies, but non-formal practical taxonomies
- Controversial exemplars can become representative of an entire class.

Risk and stigma



Design

- Group one as the 'client': biobanking and genomics and aquaculture
- Phase 2 competition
- Aim for wide range of 'top-of-head' views with interaction within group
- Five homogeneous, one-off focus groups.
- Recruitment, facilitation and data reduction by an independent company.
- Focus groups in 3 hours sessions; public paid, experts donate to a charity

Participants

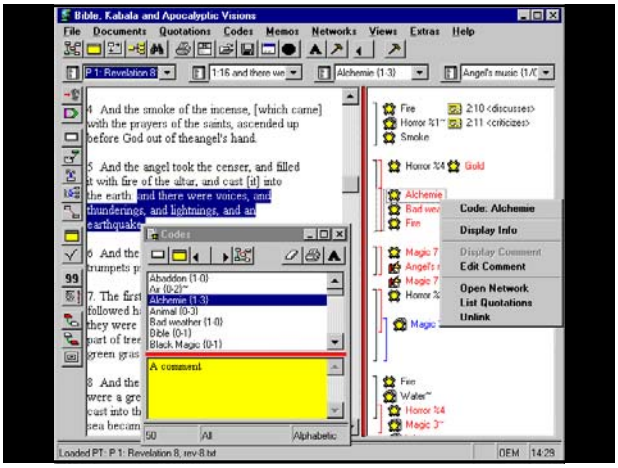
- Random 1 + 2: members of the public, recruited by random digit dialling
- NGO: recruited from non-governmental organisations with and interest in salmon
- Res/Promo: individuals involved in SG research or promotion
- Acad/Reg: Academics and regulators (DFO).

Implementation

- Consistency through moderator's guide: 'I'd like you to tell me things that come to mind when I say 'salmon genomics' and 'salmon aquaculture'.
- Coding identifies only the cases where participants provide a direct answer to salmon genomics question.
- At no point in the session did moderators mention transgenic applications or manipulation.

Qualitative data analysis

- Implementation and transcription
- Data reduction: creating order out of data
- Coding and commenting: attaching markers to concepts within the text
- Paper contains comments developed around the codes to summarise meaning



Results

Literature review	Focus Groups
Food security	Commercial Influence
Harms to environment	Technological Imperative
Harms to wild fish stocks	Genomics conflated with transgenics
Lost opportunities	Foreign ownership
Safety for human consumption	Impacts on Culture/Society
Respect for boundaries (moral and cultural)	Negative public perception and NGOs as an NdustryÓ
	Salmon Ntánted by associationÓ
	Salmon welfare (individual & species)

Distribution of codes

Table 1: Distribution of codes across groups

Group	Manip-ulation of nature	Salmon as food source	Profits	Fish escape	Rate of change	Costs/ economics	Impacts on wild salmon	Other environ-mental concerns	Lack of public knowledg e	First Nations interests	Privatiz-ation of a common good	Misc. comments
Random1	6	3	1	1	0	0	0	0	0	0	0	0
Random2	3	9	0	1	0	3	5	6	0	0	0	1
NGO	8	0	0	1	0	0	3	1	1	4	0	0
Fund/Res	10	10	11	0	10	3	0	0	3	0	6	0
Reg/Acad.	0	0	0	1	0	3	0	0	3	0	0	15

Summary

- Genomics more than the study of genes and their function
- Understood as genetic manipulation and in terms of commercial applications and social and environmental impacts
- Conflation separate from judgements about acceptability
- The benefits of a general genomics programme creates risks of stigma.

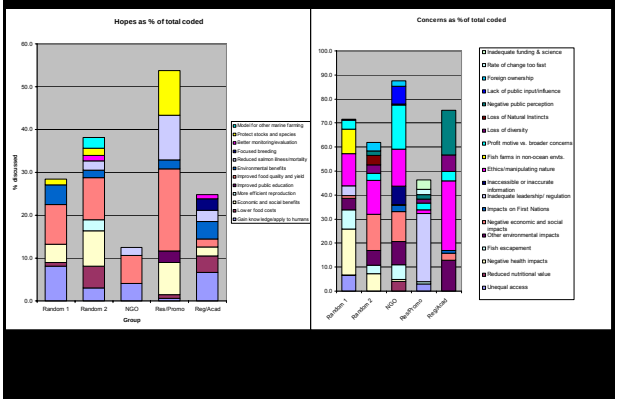
Policy implications

Model 1:

- Solution: More education, strong enforcement of distinction semantically and in practice
- Challenge: expensive and in practice the distinction is fuzzy

Model 2:

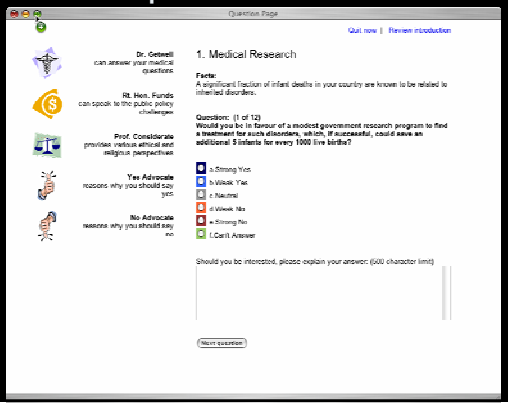
- Solution: recognise that conflation of genomics with transgenics and applications is a social fact
- Broaden public debate about acceptable applications: pharming? ugly fish?
- Challenge: risk issue management for industry



Norms Evolving in Response to Dilemmas (NERD)

- Survey site: http://yourviews.ubc.ca
- Research group site: http://robo.ethics.ubc.ca/~pad/NERD

The Experimental Platform



QuickTime™ and a
TIFF (LZW) decompressor
are needed to see this picture.

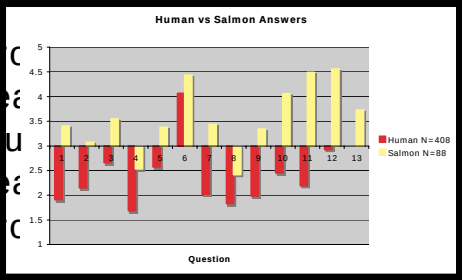
Support for experiments:

- Dynamic DataBase-driven Site
  - Large Structured Heterogeneous Data Set
  - Fixed framework
    - Add new content to change survey
  - Real Time Graphic Feedback
- Population split
- "Ratchet" web browser (client)
- Client-side timing
- Open-source (extensibility)

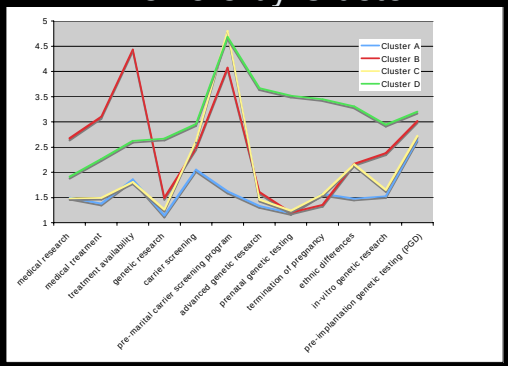
2. Context

- Two Contexts
  - Human Health (complete)
    - ß-Thalassaemia in Cyprus
  - Food (in progress)
    - Salmon Genomics & Aquaculture
- Parallel Surveys
  - In different domains
    - Bioethics; Environmental ethics

Comparing Contexts



Answers by Cluster



Conclusions

- Innovations in methods: Naturalized Unstructured Deliberative Engagement (NUDE)
- Use internet and multi-media
- Recognise consensus impossible